



# HIV/AIDS

## Native Americans

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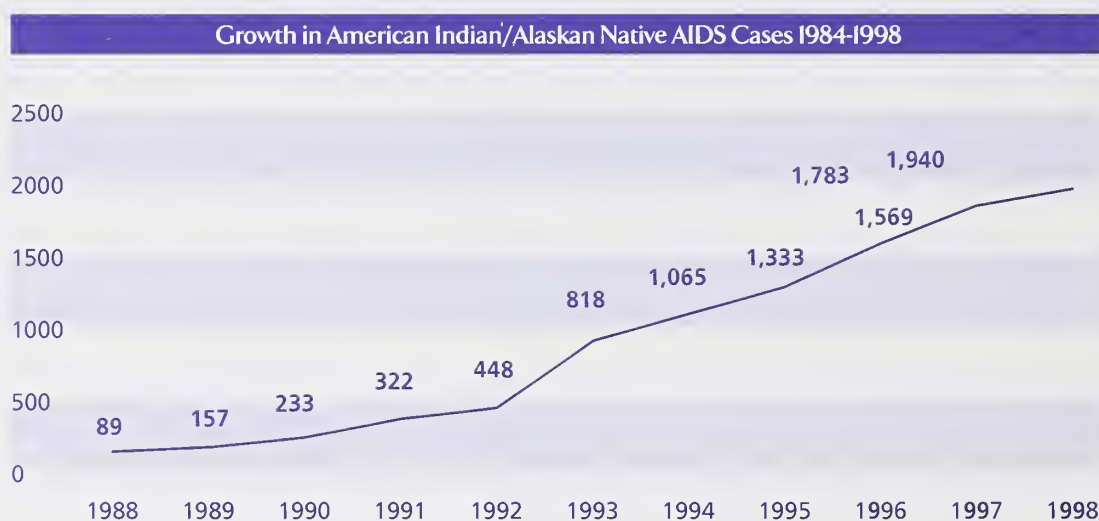
 NATIONAL MINORITY AIDS COUNCIL

MH01D4447

## Disparities in Health among Ethnic and Racial Minorities Persist

- Despite the fact that the health of the United States (U.S.) population has improved significantly over the last 50 years, ethnic and racial minority groups still continue to lag behind the white population, experiencing substantial disparities in health outcomes on many significant indicators.<sup>1</sup>
- The disparities in health experienced by ethnic and racial minority groups are particularly evident in the case of HIV and AIDS in the United States. Ethnic and racial minority groups in the U.S. make up 24% of the U.S. population yet they represent 67% of the new AIDS cases.<sup>1</sup>
- The AIDS epidemic among Native Americans – American Indians and Alaska Natives – continues to grow. As of December 1996, the Centers for Disease Control and Prevention (CDC) had reported a cumulative total of 475 cases of HIV infection and 1,569 cases of AIDS among Native Americans. By December 1998 – a two-year period – the cumulative HIV infection cases increased by 33% to 632, and the AIDS cases increased by 24% to 1,940.<sup>2</sup>

- It is probable that the number of AIDS and HIV cases among Native Americans is higher than what has been reported to the CDC due to misclassification of the ethnicity of Native Americans by health workers and officials as either white, Hispanic or Asian.<sup>3</sup>
- The Native American population is disproportionately affected by many social and behavioral factors that contribute to the disparities in health outcomes and increased vulnerability for HIV infection. The Native American population is relatively young, and has high rates of poverty, sexually transmitted diseases and drug and alcohol abuse.<sup>4</sup>
- Moreover, the policy of forced relocation of Native Americans throughout the U.S. and the attempts to relocate them to urban areas, coupled with the racism and discrimination they encountered, have led to a legacy of high rates of poverty, unemployment, welfare dependency, obesity, diabetes, alcoholism, substance abuse and family violence.<sup>5</sup>



<sup>1</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998.

<sup>2</sup> Rowell, Ronald, M. and Bouey, Paul, D. "Update on HIV/AIDS among American Indians and Alaska Natives". The HIS Primary Care Provider, Volume 22, Number 4, April 1997, p.49; Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Tables 7 & 8, pp.16-17.

<sup>3</sup> Rowell, Ronald, M. and Bouey, Paul, D. "Update on HIV/AIDS among American Indians and Alaska Natives". The HIS Primary Care Provider, Volume 22, Number 4, April 1997, p.49;

<sup>4</sup> Centers for Disease Control and Prevention, "HIV/AIDS Among American Indians and Alaskan Natives – United States, 1981-1997", MMWR 47 (08) 154-160, March 6, 1998, p.156.

<sup>5</sup> Office of Research on Women's Health, Office of the Director, National Institutes of Health, Women of Color Health Data Book: Adolescents to Seniors, NIH Publication No. 98-4247, pp. 5-8, 2-4

## Native American Population is Diverse with over 500 Tribes

- Native Americans – American Indians and Alaska Natives – were the original inhabitants of America and make up 1% of the total U.S. population. There are an estimated 2.3 million Native Americans in the U.S.
- Approximately half of the Native American population lives on or near reservations; the other half resides in other rural areas and in urban areas.
- The Native American population includes 554 tribes, which are recognized by the federal government. There are other tribes, mostly in California, that are not federally recognized ones.
- Native American sub-populations are culturally diverse and speak more than 300 distinct languages.

### Ten Reservations with the Largest Number of American Indians, Eskimos, and Aleuts: 1990

Navajo, AZ, NM, UT	143,405
Pine Ridge, NE, SD	11,182
Fort Apache, AZ	9,825
Gila River, AZ	9,116
Papago, AZ	8,480
Rosebud, SD	8,043
San Carlos, AZ	7,110
Zuni Pueblo, AZ, NM	7,073
Hopi, AZ	7,061
Blackfeet, MT	7,025

- In 1990, the only tribes with more than 100,000 persons were Cherokee (308,000), Navajo (219,000), Chippewa (104,000) and Sioux (103,000). Approximately 16% of all American Indians reported themselves as Cherokee, 12% as Navajo and 6% as Chippewa and Sioux.

- The Choctaw (82,000), Pueblo (53,000) and Apache (50,000) had populations of at least 50,000 persons. The Choctaw accounted for 4% of the American Indian population. The Iroquois Confederacy (49,000), Lumbee (48,000) and Creek (44,000) all had 43,000 or more persons.

## Close to One Half of Native Americans Live West of the Mississippi River

- Two of every three Native Americans, including Eskimos and Aleuts lived in the 10 States with the largest American Indian population in 1990.
- Of these States, only North Carolina, Michigan and New York are east of the Mississippi River.
- In 1990, more than one half of the Native American population lived in just six States: Oklahoma, California, Arizona, New Mexico, Alaska and Washington.
- Oklahoma (252,000) was the State with the largest American Indian population in 1990, followed by California (242,000), Arizona (204,000) and New Mexico (134,000).

### Ten States with the Largest Number of American Indians, Eskimos, and Aleuts: 1990 (Thousands)

Oklahoma	252
California	242
Arizona	204
New Mexico	134
Alaska	86
Washington	81
North Carolina	80
Texas	66
New York	63
Michigan	56

U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Who's Who in America*, September 1995, p. 100.

U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Who's Who in America*, September 1995, p. 9.

Collins, Karen Scott, and Hall, Allison, Neuhaus, Charlotte, *U.S. Minority Health: A Chartbook*, The Commonwealth Fund, May 1999, pp. 30-9.



## The Native American Population is a Young and Growing One

- It is projected that by the year 2030 the Native American population will grow by 44% to 2.9 million persons.<sup>8</sup>
- Thirty-nine (39%) percent of the Native American population was under 20 years of age in 1990 compared with 29% of the total U.S. population.
- About 8% of all Native Americans were 60 years old and over in 1990, compared to 17% for the total U.S. population.
- In 1990, the median age of the Native American population was 26 years compared with 33 years for the total U.S. population. The median age for Alaska Natives was 24 years. The median age for Native Americans living on reservations and trust lands was even younger, 22 years. Among the 10 largest reservations, Rosebud (SD) had the youngest median age followed by Pine Ridge (SD), both at approximately 19 years.
- The Native American population is younger partly due to higher fertility rates compared with the fertility rates of the total U.S. population. Native Americans have 69 live births per 1,000 women ages 15-44 compared to the national rate of 65 live births per 1,000 women ages 15-44.<sup>9</sup>

## Native Americans Have a Higher Proportion of Female-headed Households

- In 1990, six in ten Native American families had both a husband and wife present, compared with 8 in ten for the total U.S. families. Fifty eight percent of Alaska Native families had a husband and wife present.
- The proportion of Native American families that were female headed was 27% compared with 17% of the total U.S. families.
- Native American families were slightly larger than all U.S. families, with 3.6 persons per family compared with 3.2 persons per all U.S. families. Among the 10 largest reservations and trust lands, the median number of persons per

family unit ranged from 4.6 for Zuni Pueblo, AZ-NM, to 3.5 for Blackfeet, MT.

- In 1990, Native American married couples (54%) were less likely to have children less than 18 years old compared to all married U.S. couples (70%).<sup>10</sup>

## Native Americans Experience Lower Educational Attainment

- In 1990, 66% of the Native American population 25 years old and over were high school graduates or higher, compared with 75% of the total U.S. population in the same age group. Sixty three percent of Alaska Natives had completed high school or higher. The proportion of high school graduates for Native Americans living on reservations and trust lands was 54% overall, and the range for the ten largest reservations and trust lands was from 37% to 66%.
- In 1990, about 8% of Native Americans completed a bachelor's degree or higher compared with 20% of the total U.S. population. Alaska Natives had lower educational attainment with 4% being college graduates with a bachelor's degree or higher.<sup>11</sup>

## Native Americans Have Lower Median Incomes and Higher Poverty Rates

- In 1990 the median family income of Native Americans was \$21,750 compared with \$35,225 for the total U.S. population.
- For married couples, the median income was \$28,287 for Native Americans compared with \$39,584 for all married couples in the U.S.
- For female headed households the median family income was \$10,742 for Native Americans and \$17,414 for all female headed households in the U.S.
- About 31% of Native Americans were living below the federal poverty level in 1990, compared to 13% of the total U.S. population. Twenty three percent of Alaska Natives lived in poverty while 51% of the Native Americans living

<sup>8</sup> U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We the First Americans*, September 1993, p. 3.

<sup>10</sup> Collins, Karen Scott, and Hall, Allyson, Neuhaus, Charlotte, *U.S. Minority Health: A Chartbook*, The Commonwealth Fund, May 1999, pp. 28-29.

<sup>11</sup> U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We the First Americans*, September 1993, p. 4.

on reservations and trust lands lived in poverty. There were vast differences in poverty rates among the 10 largest reservations from 49% in the Hopi, AZ to 66% in Pine Ridge, SD reservation.

- In 1990, twenty seven percent of Native American families lived in poverty compared to 10% of all U.S. families. Twenty one percent of Alaska Native families lived in poverty.
- Fifty percent of female-headed Native American families lived in poverty compared with 31% of all U.S. female-headed households.

## Health Insurance and Medicaid Coverage

- Publicly funded health care coverage is very important to Native Americans because of the high rates of poverty, in this population.
- In 1996, 18.1% of Native Americans had no health insurance coverage, 47.7% had private insurance and 39% were enrolled in Medicaid.
- All Native Americans that are members of federally recognized tribes are eligible to receive health care services through the Indian Health Service (IHS).
- IHS estimates that 1.4 million Native Americans were eligible for its services in 1996, most of whom live on reservations. This is about three-fifths of the Native American population in the U.S. About 26% of these patients were Medicaid eligible.
- Under law, States are required to provide Medicaid coverage for Native Americans if they are eligible whether or not they live on or near a reservation or in an urban area and whether or not they are eligible for IHS services.
- Medicaid is an important program for Native Americans because it provides health care coverage for low-income persons and is the largest source of financing for HIV/AIDS care in the United States.

■ Medicaid is an important source of revenue for Native American health facilities. In 1997, IHS and tribally operated facilities were projected to receive \$184.3 million in Medicaid reimbursements. This is about 10% of the \$1.8 billion appropriated for IHS and tribally operated health facilities. While the IHS budget is based on annual appropriations, Medicaid is an entitlement program and will therefore play an increasingly important role in funding for IHS and tribal health facilities.

- The shift of Medicaid beneficiaries to Medicaid managed care programs by states will impact IHS, tribal health, and urban health programs. Under the Balanced Budget Act of 1997, States can require most Medicaid beneficiaries to enroll in a managed care organization (MCO) or primary care case-management organization (PCCM). However States can only require Native Americans to receive services through a MCO or PCCM if the MCO or PCCM is an IHS, tribally operated or urban health program.
- States have the authority to require Native American Medicaid beneficiaries to enroll in MCOs or PCCMs under section 1115 demonstration or section 1915(b), Medicaid waivers.<sup>12</sup>

## Alcoholism, and Family Violence among Native Americans

- In 1991, mortality rates related to alcoholism were high among Native American populations. The alcohol related death rate for Native American males 55-64 years of age was 139 per 100,000 compared to a rate of 33 per 100,000 for white men. Among Native American women the alcohol related death rates were 21 per 100,000 for those ages 25 to 34 and 65 per 100,000 for those 45 to 54 years of age. In contrast the alcohol related deaths for white women were fewer than 10 per 100,000.
- In 1996 chronic liver disease and cirrhosis of the liver was the 5th leading cause of death for Native American men and the 6th leading cause of death for Native American women in 1993. The death rates for Native American

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<sup>12</sup> Schneider Andy and Martinez Joann. Native Americans and Medicaid: Coverage and Financing Issues. The Center on Budget and Policy Priorities for The Kaiser Commission on Medicaid and the Uninsured. December 1997, pp. 1-12

women due to chronic liver disease and cirrhosis of the liver are four times the rate for white women.<sup>13</sup>

- Physical and sexual assaults, and histories of childhood sexual abuse are alarmingly high among women with or at high risk of HIV/AIDS. Native American women are particularly vulnerable given the high rates of violence (16%) and severe violence (7%) reported in marital relationships among Native Americans.<sup>14</sup>

## Sexually Transmitted Disease among Native Americans

- According to the CDC, since 1990, rates of primary and secondary syphilis have declined among all racial and ethnic groups except Native Americans.
- In 1997 the rates of primary and secondary syphilis were 2.3 among male and 1.8 among female Native Americans per 100,000 population as compared to 0.6 among male and 0.5 among female whites.
- Among Native Americans the highest rates of primary and secondary syphilis were among males ages 25-29 years (6.3 per 100,000) and females ages 20-24 years (5.2 per 100,000).<sup>15</sup>
- In 1997, the rates of gonorrhea per 100,000 population were 67.0 among Native American males as compared to 19.5 among white males, and 131.4 among Native American females as compared to 32.3 among white females.
- Among Native Americans, the highest rates of gonorrhea for males were for those ages 20-24 (224.6 per 100,000) and among females for those ages 15-19 (554 per 100,000).<sup>16</sup>

## HIV/AIDS among Native Americans

### Cumulative and New AIDS Cases

- Through December 1998, the Centers for Disease Control and Prevention (CDC) reported 688,200 cumulative AIDS cases in the United States, its dependencies, possessions

and associated nations. Of that total, Native Americans accounted for 1,940 cases or .28% of the total AIDS cases reported through 1998.<sup>17</sup>

- In the same year a total of 48,269 new AIDS cases were reported in the U.S. Native Americans accounted for 148 or .3% of these new AIDS cases
- Native American men made up .31% of the new AIDS cases among males, Native American women represented .27% of the new AIDS cases reported among females and Native American children made up 0% of the new AIDS cases among children in the U.S.

### AIDS Cases per 100,000 Population

- Native Americans have the fourth highest AIDS case rate per 100,000 population among adults and adolescents (9.7) — almost the same as the rate among whites (9.9) in 1998.
- Native American males have an AIDS case rate of 15.7 per 100,000 population compared with the rate of 17.8 per 100,000 population for white males.
- Native American females have an AIDS case rate of 3.8 per 100,000 population, compared with white females who have a rate of 2.4 per 100,000 population.
- The AIDS case rate among Native American children less than 13 years of age was 0.0.<sup>18</sup>

### Residence Trends

- According to the CDC, in 1997, more than half (53%) of the Native Americans with AIDS resided in five states at the time of their AIDS diagnosis: California (25%), Oklahoma (11%), Washington (7%), Arizona (6%) and Alaska (4%).
- The five metropolitan statistical areas with the highest percentages of Native Americans with AIDS were San Francisco, CA (6%), Los Angeles-Long Beach, CA (6%), Seattle-Bellevue-Everett, WA (4%), Tulsa, OK (4%) and San Diego, CA (3%).

<sup>13</sup> Collins, Karen Scott, and Hall, Allyson, Neuhaus, Charlotte, U.S. Minority Health: A Chartbook, The Commonwealth Fund, May 1999, p. 43; Office of Research on Women's Health, Office of the Director, National Institutes of Health, Women of Color Health Data Book: Adolescents to Seniors, NIH Publication No. 98-4247, pp. 43 & 54.

<sup>14</sup> Office of Research on Women's Health, Office of the Director, National Institutes of Health, Women of Color Health Data Book: Adolescents to Seniors, NIH Publication No. 98-4247, and p.4.

<sup>15</sup> U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, Sexually Transmitted Disease Surveillance 1997, pp. 51, 98 & 99.

<sup>16</sup> U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, Sexually Transmitted Disease Surveillance 1997, pp. 82 & 83.

<sup>17</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Table 7, p. 16

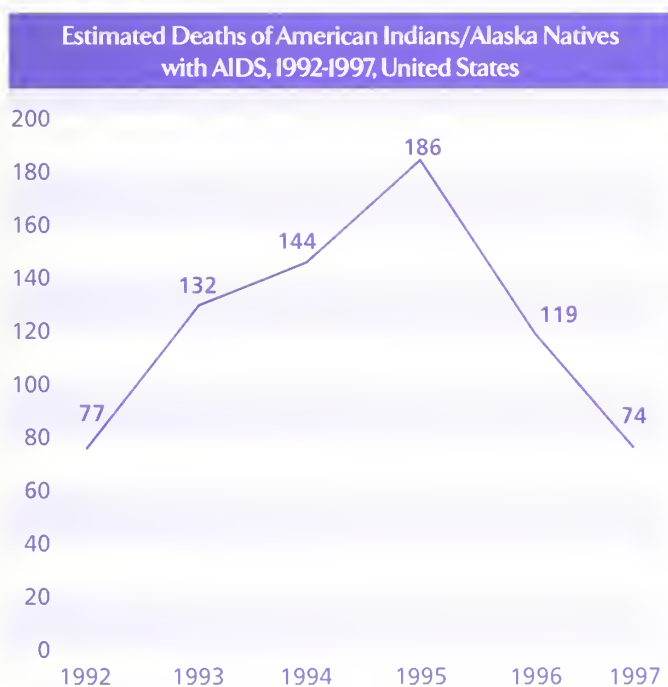
<sup>18</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Table 19, p.29.



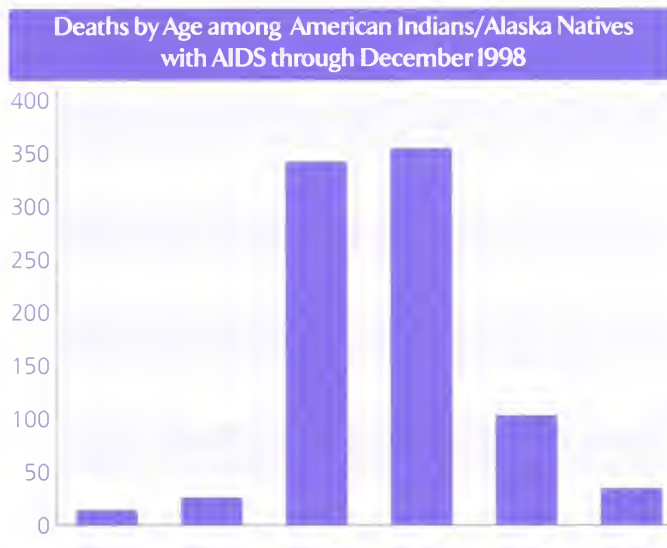
- A lower proportion of Native Americans with AIDS resided in metropolitan areas with populations greater than one million compared with all persons with AIDS (56% versus 77% respectively).
- A higher proportion of Native Americans with AIDS resided in rural areas with populations less than 50,000 compared to all persons with AIDS (19% versus 6% respectively).<sup>1</sup>

#### AIDS Mortality

- The CDC reported a cumulative total of 410,800 deaths due to AIDS through December 1998 – approximately 60% of the total persons diagnosed with AIDS since the beginning of the epidemic.
- Through December 1998, 1,035 deaths due to AIDS were reported among Native Americans, accounting for .25% of the total U.S. deaths and 53% of the 1,940 cumulative cases of AIDS reported among Native Americans.



- Despite the advances in AIDS drug therapies that have led to dramatic drops in AIDS deaths since 1996, ethnic and racial minorities continue to lag behind whites. Between 1996 and 1997 the deaths due to AIDS dropped 45% overall compared to 53% for whites, and 41% for Native Americans.<sup>2</sup>
- The rate of AIDS deaths per 100,000 population for Native Americans was 1.3 times that of whites. Data reported by the CDC in August 1999 indicates that AIDS deaths per 100,000 population were 4.19 for Native Americans compared to 3.32 for whites.



#### Gender

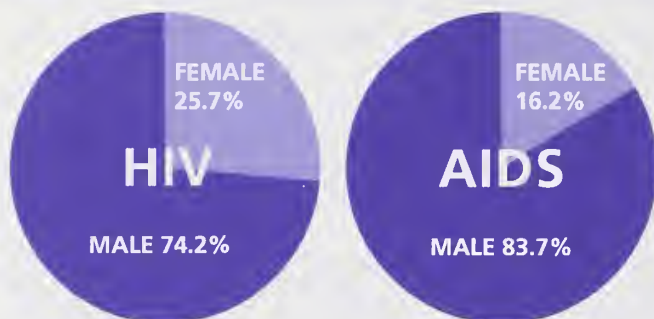
- Native American males make up 84% of the cumulative adult/adolescent AIDS cases reported among Native Americans, while females make up 16% of the cases.
- Males made up 80% and females made up 20% of the new adult/adolescent AIDS cases reported among Native Americans in 1998.
- Among Native American males, the leading exposure category for AIDS is men who have sex with men (MSM), accounting for 57% of the cumulative cases and 45% of the new AIDS cases reported in 1998.

<sup>1</sup> Centers for Disease Control and Prevention. HIV/AIDS among American Indians and Alaska Natives – United States, 1981-1997. *MMWR* 44 (08):154-160, March 1, 1998.

<sup>2</sup> Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report. National Summary, Vol. 10, No. 2, December 1, 1998. (pp. 2-3).

- Among Native American females the leading exposure category is injecting drug use (IDU), accounting for 47% of the cumulative AIDS cases and 53% of the new AIDS cases.

**Cumulative HIV Infections and AIDS Cases Compared by Gender, American Indians/Alaskan Natives, December 1998**



#### Age

- The highest numbers of AIDS cases among Native Americans are concentrated in persons ages 30-34 (505).
- The highest numbers of HIV cases among Native Americans are concentrated in persons ages 25-29 (145).<sup>21</sup>

### HIV/AIDS among Native Americans Males

#### Cumulative AIDS Cases

- In 1998, a cumulative total of 570,425 cases of AIDS among adolescent/adult males were reported in the U.S. Native Americans accounted for 1,601 cases or .28% of the cumulative total.
- Of the cases among Native American men, 57% were attributed to men having sex with men (MSM), 16% to injection drug use (IDU), 17% were due to men who have sex with men and inject drugs, 2% were attributed to heterosexual contact and 2% due to risk not reported/identified.
- Of the cases of heterosexual contact, one-third were infections due to sex with an injecting drug using female and 64% were due to having sex with an HIV+ person whose risk was not reported/identified.

#### New AIDS Cases

- Of the 36,886 new AIDS cases reported among men in 1998, .3% (117) were among Native Americans.
- Of these cases, 45% were due to men having sex with other men (MSM), 21% were due to injecting drug use (IDU), 14% were due to MSM and IDU, 2% were due to heterosexual transmission, and 16% of these cases were due to risk not reported/identified.
- Of the heterosexual transmission cases, all were due to having sex with an HIV+ person whose risk was not reported/identified.<sup>22</sup>

#### Cumulative HIV Cases

- In 1998, a cumulative total of 76,886 cases of HIV among adolescent/adult males were reported in the U.S. Native Americans accounted for 461 or .6% of the cumulative total.
- Of the cases among Native American men, 50% were attributed to men having sex with men, 15% were due to injection drug use, 13% were due to men who have sex with men and inject drugs, 5% were through heterosexual contact and 16% were due to risk not reported/identified.
- Of the cases of heterosexual contact, 45% were infections due to sex with an injecting drug using female and 55% were due to having sex with an HIV+ person whose risk was not reported/identified.

#### New HIV Cases

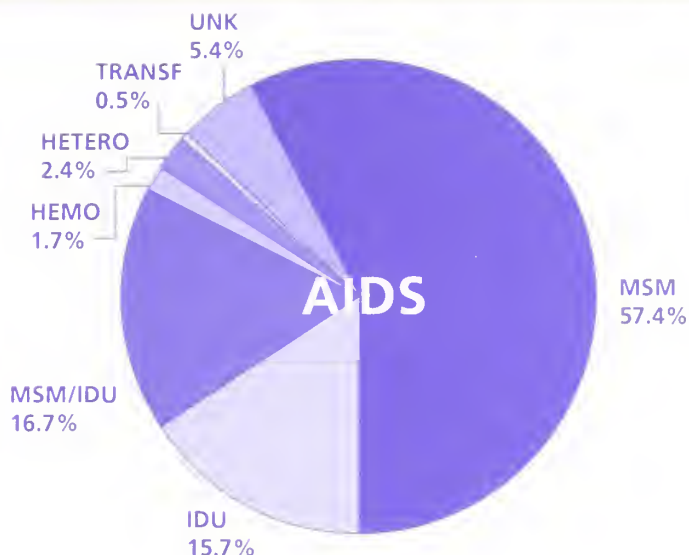
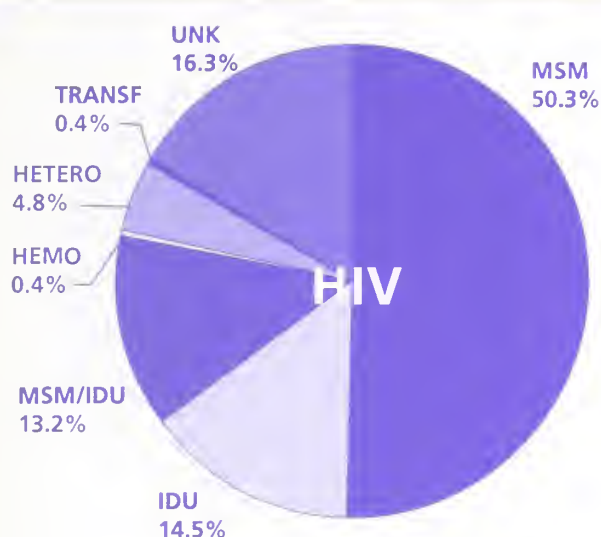
- Of the 13,031 new HIV cases reported among men in 1998, .66% (87) were among Native Americans.
- Of these cases, 57% were due to men having sex with other men (MSM), 13% were due to injecting drug use (IDU), 7% were due to MSM and IDU, 2% were due to heterosexual transmission, and 21% of the cases were due to risk not identified.
- Of the heterosexual transmission cases, 50% were due to sex with an injecting drug user, and 50% were due to having sex with an HIV+ person whose risk was not reported/identified.<sup>23</sup>

<sup>21</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Table 21, p. 30.

Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Tables 7 & 8, pp. 16-17.

<sup>22</sup> Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, Year-end edition, Vol. 10, No. 2, December 1998, Tables 9 and 10, pp. 18-19.





## HIV/AIDS among Native American Females

### Cumulative AIDS Cases

- As of December 1998 a cumulative total of 109,311 adolescent/adult females have been diagnosed with AIDS in the U.S. Native American women made up .28% (310) of the cumulative number of AIDS cases reported among females.
- Of these cases, 47% were due to injecting drug use; 36% were due to heterosexual transmission and 13% were due to risk not reported/identified.
- Of the cases of heterosexual transmission, 50% were related to having sex with an injecting drug user, 14% were due to having sex with a bisexual man and 34% were due to having sex with an HIV+ person whose risk was not reported/identified.

### New AIDS Cases

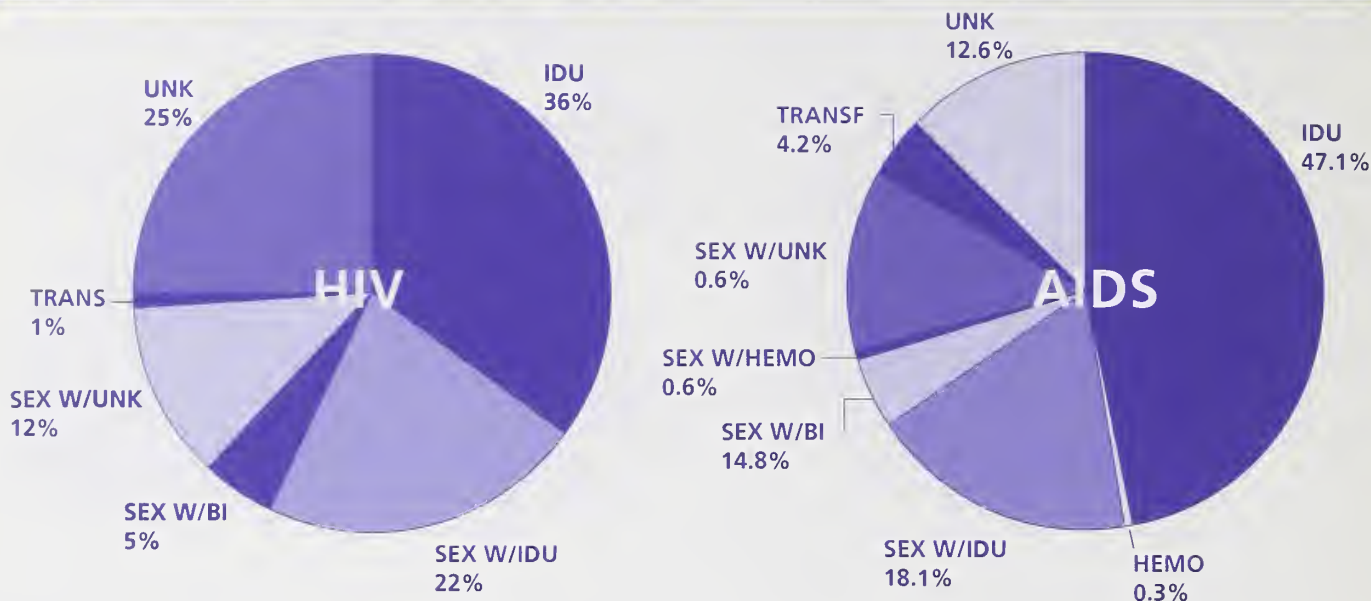
- In 1998, there were a total of 10,998 cases of AIDS reported among adolescent/adult females in the U.S. Native American women made up .27% (30) of these cases.

- Approximately 53% of the AIDS cases reported among Native American women in 1998 were due to injecting drug use, 13% were due to heterosexual contact, and 33% were due to risk not reported/identified.
- Of the cases of heterosexual transmission, 75% were related to having sex with an injecting drug user, and 25% were due to having sex with an HIV+ person whose risk was not reported/identified.

### Cumulative HIV Cases

- In 1998, a cumulative total of 27,806 cases of HIV among adolescent/adult females were reported in the U.S. Native American women accounted for 160 or .6% of the cumulative total.
- Of the cases among Native American women, 36% were attributed to injection drug use, 39% were due to heterosexual contact and 25% were due to risk not reported/identified.

## Cumulative Female Adult American Indian/Alaskan Native Cases by Exposure Category, December 1998



- Of the cases of heterosexual contact, 56% were infections due to sex with an injecting drug user, 13% were due to sex with a bisexual male and 31% were due to having sex with an HIV+ person whose risk was not reported/identified.

### New HIV Cases

- Of the 6,051 new HIV cases reported among women in 1998, .4% (23) were among Native American women.
- Of these cases, 26% were due to injecting drug use (IDU), 26% were due heterosexual transmission, and an alarming 48% of the cases were due to risk not reported/identified.
- Of the heterosexual transmission cases, 50% were due to sex with an injecting drug user, 17% to sex with a bisexual male and 33% were due to having sex with an HIV+ person whose risk was not reported/identified.

## HIV/AIDS among Native American Children

### Cumulative AIDS Cases

- As of December 1998 a cumulative total of 8,461 among children less than 13 years of age have been diagnosed with AIDS in the U.S. Native Americans made up .33% (28) of the cumulative number of AIDS cases reported among children.
- Of these cases, 96% were due to mother to child (perinatal) transmission, and 4% were due to hemophilia/coagulation disorder.
- Of the cases of mother to child transmission, 44% were related to the mother's injecting drug use, and 26% were due to the mother having sex with an injecting drug user. An additional 11% were due to the mother having sex with an HIV+ person whose risk was not identified/reported and 19% were due to an HIV+ mother whose risk was not reported/identified.

### New AIDS Cases

- In 1998, there were a total of 382 cases of new AIDS reported among children less than 13 years of age in the U.S. There were no new cases of AIDS reported among Native American children.

### Cumulative HIV Cases

- In 1998, a cumulative total of 1,875 cases of HIV among children were reported in the U.S. Native American children accounted for 11 cases or .59% of the cumulative total.
- Of the cases among Native Americans, 73% were due to mother to child (perinatal) transmission, 9% were due to hemophilia/coagulation disorder and 18% were due to risk not reported/identified.
- Of the cases of mother to child transmission, 38% were related to the mother's injecting drug use, 25% were due to the mother having sex with an injecting drug user, 12.5% were due to the mother having sex with a bisexual male. In addition, 12.5% were due to mother having sex with a person with hemophilia and 12.5% were due to an HIV+ mother whose risk was not reported/identified.

### New HIV Cases

- Of the 309 new HIV cases reported among children in 1998, none were reported among Native American children.

### Current HIV Case Reporting May Under-count Native American Cases

- HIV reporting does not provide a good indicator of the trends in the epidemic among Native Americans for a variety of reasons:
- Currently 33 states and jurisdictions have confidential HIV reporting systems and report HIV infection cases to the CDC. Confidential HIV case reporting is based reporting cases by name.

- Of the ten states that account for two-third of the Native American population - Oklahoma, California, Arizona, New Mexico, Alaska, Washington, North Carolina, Texas, New York and Michigan - three do not report HIV infection cases (Alaska, California, and Washington). New York just began implementation of confidential HIV case reporting in January 1999, and New Mexico began in January 1998. Texas only reports pediatric HIV cases.

- Other factors that lead to under-reporting of Native American HIV cases include misclassification of Native Americans as white, Asian or Hispanic by health workers and officials, and the lack of inclusion of Native Hawaiians in HIV and AIDS reports among Native Americans. In addition, most tribes do not report HIV/AIDS surveillance data to the Indian Health Service (IHS), to state health departments or to the CDC. The IHS does not routinely collect such information from the tribes. The problems in case reporting by the IHS to state health departments and CDC also leads to under-counting.<sup>14</sup>

- HIV case reporting data must therefore be used with caution, particularly when it is used to justify service needs and funding allocations for HIV prevention and care service programs targeted to specific populations.

- Surrogate markers for HIV infection should also be used to project trends and to target funding, including data on the rates of infection from other sexually transmitted diseases (STDs), teen pregnancy, and trends in alcohol and substance use and abuse, including injecting drug use.

### Barriers to HIV Prevention and Care Services for Native Americans

#### Prevention

- To curb the spread of HIV infection among Native Americans HIV prevention must be a top priority. Targeted culturally and linguistically appropriate prevention interventions are needed. To make an impact, these interventions must be on-going and sustained and consider the social, economic, cultural, religious, spiritual, and

<sup>14</sup> Rowell, Ronald M. "Contrary to the Press Coverage of CDC's Report on AIDS in Native Americans, the Epidemic is Not Leveling Off in Our Population." *In The Wind: HIV/AIDS in Native America*. Volume 9, Number 2, Spring/Summer 1998, pp1-2.



geographic contexts in which the diverse sub-populations of Native Americans live.

- HIV prevention efforts must take into consideration the rapid population growth and the diversity of Native Americans sub-populations that vary by region, tribal origin, language, urban/rural and reservation residence, and culture.
- The federal government's emphasis on multicultural outreach approaches in funding HIV/AIDS prevention programs may result in ethnic minority groups competing among themselves for limited resources. Without a Native American spokesperson, outreach worker or health educator, Native Americans may find it difficult to identify HIV as something that can impact them.<sup>25</sup>
- The prevention community planning process is the major vehicle for the distribution of federal prevention funding to states and localities.
- Despite the diversity of the Native American population, there are few Native Americans involved in the HIV prevention community planning process. In a March 1998 report on the progress of Prevention Community Planning, the CDC indicated that Native Americans represent 5% of the total 1,064 members of community planning groups nationwide. This means that about 53 Native Americans nation-wide were members of prevention community planning groups (CPGs).
- According to the CDC, the level of program support currently directed to racial and ethnic minority communities, injecting drug user (IDUs) populations, men who have sex with men (MSM), and HIV infected individuals is substantially less than what the current epidemiological trends indicate is necessary.
- To achieve true parity inclusion and representation in the prevention community planning process, CDC must take steps to ensure that the number and the meaningful participation of Native Americans on these groups be increased significantly. In some states, the regional distribution of the CPGs does not include remote rural areas or reserva-

tions. When they meet, people from remote rural and reservation areas must travel long distances to participate in the CPG meetings.<sup>26</sup>

- The community planning process does not take tribal sovereignty into consideration. The jurisdictions that are responsible for implementation of community planning are state and territorial governments and directly funded cities. Because tribes maintain a government to government relationship with the federal government, there is a serious lack of tribal involvement in the community planning process.
- Surveillance plays a key role in the allocation of funding for HIV prevention services. However, there are serious limitations in the accuracy of the HIV/AIDS surveillance data for Native Americans. HIV case reporting underestimates the number of Native Americans with HIV and therefore does not provide a good indicator of the trends in the epidemic among Native Americans.
- An unreleased analysis of FY 1999 CDC HIV/AIDS budget by race and ethnicity indicates that about .8% (\$3 million) of \$353 million in prevention dollars are targeted specifically to Native Americans.

#### **HIV Care**

- A variety of factors contribute to the disparities in AIDS incidence and mortality experienced by Native Americans. These include late identification of HIV infection; less access to experienced HIV/AIDS physicians, less access to HIV therapy that meets the Public Health Service Guidelines and lack of health insurance to cover HIV care and medications.
- HIV/AIDS like so many infectious diseases to which whites have exposed Native Americans is viewed as a "white man's disease". Moreover HIV and AIDS do not have meaning in indigenous languages and therefore cannot be discussed in local languages nor can indigenous healing processes be applied to them.

<sup>25</sup> Office of Research on Women's Health, Office of the Director, National Institutes of Health, Women of Color Health Data Book: Adolescents to Seniors, NIH Publication No 98-4247, pp 4-5.

<sup>26</sup> The National Native American AIDS Prevention Center, Seasons, Autumn 1996, pp. 2-3.

- The lack of confidentiality in IHS clinic also serves a barrier to HIV counseling and testing.
- The failure of health care providers and substance abuse programs to incorporate healing elements from Native cultures, such as the medicine wheel, into their service delivery creates barriers to care. Euro-American treatment models that focus on single disease rather than the whole person are viewed as another form of oppression.
- Social-economic problems such as poverty, alcoholism and substance abuse, and low self-esteem may interfere with the ability of many Native Americans to seek preventive care, particularly when it is delivered by culturally insensitive providers and the services are located at great distances.

### Recommendations

- Increase HIV/AIDS prevention and care resources specifically targeted to Native American populations and communities, and indigenous community based organizations and institutions to provide culturally specific and culturally competent HIV prevention and care services.
- Provide CDC funding for targeted prevalence studies of HIV and AIDS among Native Americans.
- CDC should develop a uniform, standard HIV/AIDS surveillance system for Native Americans throughout the United States. This should be done in collaboration with the IHS; National Native American AIDS programs, the National Indian Health Board, the National Council of Urban Indian Health, the National Alliance of State and Territorial AIDS Directors and the Council of State and Territorial Epidemiologists.
- Provide CDC funding to target additional resources to indigenous national, regional and local Native American community based organizations (CBOs) for HIV prevention services targeted to highly impacted and emerging Native American sub-populations. These include but are not limited to men who have sex with men, youth, women, and injecting drug users and urban and rural populations.
- Strengthen prevention capacity in Native American communities, through the CDC's Directly Funded Minority and Other CBOs Program, and the National/Regional Minority Organizations Program, technical assistance programs. There should also be an infusion of funding for the Communities of Color Initiative with the necessary funds to carry out a targeted and tailored, Native American Prevention Initiative.
- Provide additional CDC funding to indigenous national, regional and local Native American community based organizations to provide training and technical assistance to increase the participation, inclusion and representation of Native Americans in HIV prevention community planning.
- Provide additional Health Resources & Services Administration (HRSA) funding to indigenous national, regional and local Native American community based organizations to provide training and technical assistance to increase the participation of Native Americans in Ryan White CARE Act planning councils.
- Develop, and expand the initiatives aimed at training Native American health professionals on the state-of-the-art HIV treatment and care, through the HIV Centers of Excellence and other vehicles. HRSA should direct funds towards the development and implementation of a plan to increase the number of Native American health professionals who specialize in HIV/AIDS and primary care in medically under-served urban and rural communities, and in community health centers.
- Provide direct funding from HRSA to indigenous national, regional and local Native American community based organizations to provide cultural competency technical assistance and training to health care providers serving Native Americans and to develop and implement comprehensive outreach and treatment education programs targeted to Native Americans. Where necessary these programs should incorporate traditional healing concepts and be provided in the indigenous languages of the Native Americans to be reached.

- Increase the avenues for access to resources under the Ryan White CARE Act for Indian Health Service, tribal and reservation based facilities providing care to Native Americans living with HIV disease.<sup>27</sup>
- Increase the involvement and capacity of IHS alcoholism and substance abuse programs to provide HIV prevention and treatment services within their service delivery network to Native Americans at risk for and those living with HIV/AIDS.<sup>28</sup>
- Provide direct funding from the Substance Abuse & Mental Health Services Administration (SAMHSA) to indigenous national, regional and local Native American community based organizations to provide technical assistance on the integration of HIV prevention programs within Native American substance abuse treatment programs.
- Provide direct funding from SAMHSA to Native American community based programs to provide intensive outreach, education and HIV counseling and voluntary testing, and direct linkage to care for Native American injecting drug users.
- SAMHSA should provide funding to Native American organizations to increase the availability of drug treatment slots for Native Americans and to expand programs that provide comprehensive, culturally competent, woman-focused substance abuse treatment services, for women and their children. These programs should integrate HIV prevention and primary HIV health care into drug prevention and treatment services.
- The National Institutes of Health (NIH), Office of AIDS Research should develop a strategic plan with the relevant Institutes and the CDC to develop and implement a research agenda regarding HIV prevention in Native American communities and fund research projects that include collaborations with indigenous Native American community based organizations.
- The National Institute on Drug Abuse (NIDA) should fund research projects to study the relationship between substance use and risks for HIV infection among Native Americans.
- Develop mechanisms to increase collaboration among the IHS, tribal health systems, urban Indian clinics, and Native American AIDS programs and agencies to improve access to HIV care for Native Americans.

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<sup>27</sup> Wood, Greg, Albert, Anna, et, al, "HIV Center of Excellence" The IHS Primary Care Provider, Volume 22, Number 4, April 1997, pp. 55-56.

<sup>28</sup> Rowell, Ronald, M. and Bouey, Paul, D. "Update on HIV/AIDS Among American Indians and Alaska Natives". The HIS Primary Care Provider, Volume 22, Number 4, April 1997, p.52.





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